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**Ambivalence in digital health: Co-designing an mHealth platform for HIV care**

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**Abstract:** In reaction to polarised views on the benefits or drawbacks of digital health, the notion of ‘ambivalence’ has recently been proposed as a means to grasp the nuances and complexities at play when digital technologies are embedded within practices of care. This article responds to this proposal by demonstrating how ambivalence can work as a reflexive approach to evaluate the potential implications of digital health. We first outline current theoretical advances in sociology and organisation science and define ambivalence as a relational and multidimensional concept that can increase reflexivity within innovation processes. We then introduce our empirical case and highlight how we engaged with the HIV community to facilitate a co-design space where 97 patients (across five

European clinical sites: Antwerp, Barcelona, Brighton, Lisbon, Zagreb) were encouraged to lay out their approaches, imaginations and anticipations towards a prospective mHealth platform for HIV care. Our analysis shows how patients navigated ambivalence within three dimensions of digital health: quantification, connectivity and instantaneity. We provide examples of how potential tensions arising through remote access to quantified data, new connections with care providers or instant health alerts were distinctly approached alongside *embodied* conditions (e.g. undetectable viral load) and *embedded* socio-material environments (such as stigma or unemployment). We conclude that ambivalence can counterbalance fatalistic and optimistic accounts of technology and can support social scientists in taking-up their critical role *within* the configuration of digital health interventions.

### Introduction

Many aspects of health and care are now experienced and practiced by the use of digital technologies. The notion of ‘digital health’ refers to sociotechnical assemblages where a range of technologies are embedded in social practices of accessing health information, sharing illness experiences, supporting people with chronic diseases to engage in self-care or empowering others to take up healthy lifestyles (Lupton 2018). The new generation of mobile digital health technologies (mHealth), including smartphones, tablet computers and ‘wearables’, offer unprecedented opportunities for monitoring bodily conditions and health behaviours and instant access to personalised health data and these affordances are often interpreted by the medical and public health literature to mean that digital health will increase the quality and effectiveness of health services and bring forth emancipated citizens and patients that take responsibility for their own health (Topol 2015, WHO 2016).

Social scientists, on the other hand, have begun to articulate a number of concerns towards the increased digitisation of health. For example, it has been argued that digital technologies shift responsibility for health towards individual patients without problematizing the ‘digital divide’ (based on literacy, socioeconomic status, age, etc.) or acknowledging the social determinants of health (Fox 2017), that the over-reliance on ‘objective’ health data can undermine awareness of haptic sensations,

leading to a reductionist understanding of the self and its complex health conditions (Maturo and Setiffi 2016), and that digital technologies are producing an unprecedented ‘net of surveillance’ that extends medical power and raises serious concerns regarding data security and privacy (Rich and Miah 2016, Till 2014).

In a recent review, Ruckenstein and Schüll (2017) have argued that while the social science literature has used analytical concepts to outline potential negative consequences and concerns towards digital health, less focus has been given to reveal the inherent tensions and contradictions that are enacted in sociotechnical practices. In their ethnographic studies of self-tracking practices, Sharon (2017) and Schüll (2016) have shown how self-trackers continuously negotiate and re-calibrate their intuitions and embodied experiences with the quantified data they generate through digital devices. This underlines that a dichotomised view that emphasises either benefits or drawbacks of digital health is problematic, obscuring the complexities that are experienced when using self-care technologies (Lupton 2018). This has led some authors to propose that critical approaches towards digital health need to grasp ‘ambivalence’ to provide nuanced understandings of how people move between modes of engagement and disengagement and to outline how positive and negative consequences shift across embedding environments (Ruckenstein and Schüll 2017, Lupton 2018).

In this article, we respond to this proposal by demonstrating how ambivalence can work as a reflexive approach to evaluating the potential implications of digital health. We start by drawing attention to a renewed interest in ambivalence within sociology and organisation science where ambivalence has been conceptualised as a relational and multidimensional phenomenon that has potential to facilitate reflexivity and learning in innovation processes. This, makes it particularly useful for analyses in the digital health field, where the term ambivalence is still only used rather colloquially.

Acknowledging this potential, we introduce our empirical case and describe how we facilitated a space for ambivalence within a large-scale sociotechnical evaluation of an mHealth platform for HIV care. In this context, we initiated a co-design process with patients, clinicians and technology developers in five clinical sites across the European Union (EU) to identify the practices and needs of potential users and outline respective design specifications for the platform (Marent et al. forthcoming). Co-design participants often drew on their current uses of digital technologies to anticipate how a

prospective platform might reconfigure practices of HIV care. By embracing and honouring both positive and negative orientation towards the future object, the co-design process generated new possibilities for understanding that influenced the development of a platform prototype, which has now been introduced and is being evaluated in the five clinics.

For this article, we analyse data gathered through co-design workshops and interviews with 97 HIV patients. We demonstrate how the ambivalence within patient accounts towards the mHealth platform are related to contradictions that arise through three dimensions: quantification, connectivity and instantaneity. Furthermore, we outline how positionings towards quantified data, digital connections and instant alerts are *related to* and *balanced within* situated practices. We argue that a *relational* and *multidimensional* view of ambivalence can provide a nuanced understanding of the manifold implications and social enactments of digital health. This shows that implications and responses are neither consistently negative nor consistently positive but shift across dimensions and along the situated practices. *Cross-dimension ambivalence*, for instance, reveals that a HIV patient can value some affordances of a digital device (e.g. *instant* reminders for medication intake) while rejecting others (e.g. remote access to *quantified* blood test results). *Relationality* draws our attention to the situated practices within which such meanings emerge. For example, reminders might be particularly valued by a newly diagnosed patient who has not established a routine for medication intake. Such a patient, however, might dismiss remote access to blood test results because these are difficult to interpret and can trigger feelings of uncertainty.

We conclude by arguing that our empirical case provides evidence that ambivalence can be harnessed successfully as a reflexive approach within research and innovation processes in the digital health field. Rather than generating enthusiastic promises or fatalistic rejections, ambivalence permits and facilitates continuous movements and reinterpretation to assess the implications of digital health interventions. Ambivalence is thus understood as intrinsic to reflexivity (Walker and Shove 2007). It is part and parcel of a dynamic, critical and engaged approach that aims to understand and intervene in the configuration of digital futures.

### **Defining ambivalence**

In the sociological literature, the notion of ambivalence has been used to describe societal processes of modernisation and sociotechnical change (Bauman 1990, Beck et al. 1994, Smelser 1998). Theorising new modes of risk assessment and decision-making within situations of competing forms of knowledge and technological uncertainties, ambivalence has been offered as counterpoint to dominant rational-choice theories to consider ‘nonrational forces in individual, group, and institutional behaviour’ (Smelser 1998, p. 3). In this way, ambivalence is seen as a normal rather than a pathological state of societies and individuals that live and act under complex and uncertain circumstances.

Recent studies in sociology and organisation science have revisited ambivalence as a middle-order concept to investigate the relational, multidimensional and contradictory forces within social and organisational relationships (Hillcoat-Nallétamby and Phillips 2011, Arribas-Ayllon and Bartlett 2014, Ashforth et al. 2014, Rothman et al. 2017, Piderit 2000, Walker and Shove 2007, Benjamin 2011). These attempts to conceptualise ambivalence do differ slightly in their wordings but, nevertheless, share important aspects which we emphasise along five key features. First, ambivalence is the simultaneous experience of two (*ambi*) opposing orientations or values (*valences*) (Ashforth et al. 2014, Rothman et al. 2017). Thus, the term indicates an oscillation or tension between opposite poles of feeling and thinking, or, as Smelser (1998, p. 5: emphasis in original) argues: ‘*opposing affective orientations toward the same person, object, or symbol*’. Second, ambivalence can be understood as a phenomenon on an individual or collective level (Ashforth et al. 2014, Rothman et al. 2017). As Weick (quoted from: Ashforth et al. 2014, p. 1455) emphasises: ‘ambivalence can be a property of networks and distributed cognition as well as a property of individuals.’ It is applied as a sociological concept to describe conflicting demands inherent in social structures, and, it is stressed as a psychological concept to outline how structures can trigger contradictory experiences within individuals. Third, ambivalence is clustered along multiple dimensions in which experiences and actions take place (Piderit 2000). For instance, an object can create contradictions or value tensions by reconfiguring knowledges, social relations or spatiotemporal arrangements. Conceptualising each dimension of ambivalence as a separate continuum allows the exploration of various contradictions along different dimensions that can be analysed as ‘cross-dimension ambivalence’ (Piderit 2000). Fourth, ambivalence should not be understood as a static

but as a relational concept (Hillcoat-Nallétamby and Phillips 2011, Arribas-Ayllon and Bartlett 2014). As such, ambivalence becomes a manifestation of contradictions which stem from dynamic interactions between social actors, objects and the environments within which they are embedded. Finally, recent studies on ambivalence increasingly acknowledge its positive impact on personal growth and organisational innovation (for an overview: Rothman et al. 2017). Thus, ambivalence has been emphasised as a framework for implementing participatory research and design initiatives that account for multiple uncertainties in relation to organisational change and technological innovation (Benjamin 2011, Walker and Shove 2007). By connecting opposing orientations in an ongoing manner, ambivalence can increase reflexivity and give rise to forms of agency that defy narrow decision-making frames.

In the next section, we describe how we mobilised the potential of ambivalence in a formative co-design process to generate widespread conversation about the potential uses and implications of a specific mHealth platform for HIV care.

### **Method**

#### *Case: The EmERGE study*

The case we draw on to demonstrate the potential of ambivalence as a means of facilitating and capturing contradictions and tensions in accounts of digital health is part of the ‘EmERGE study’ (see: [www.emergeproject.eu](http://www.emergeproject.eu)), a five-year ‘Research and Innovation Action’ project funded by EU’s Horizon 2020 programme (2015-2020). EmERGE is developing, implementing and evaluating an mHealth platform to support follow-up and self-management in HIV care in five clinics (Antwerp, Barcelona, Brighton, Lisbon and Zagreb). The concept of ‘platform’ refers to online sites that enable and organise data streams, social interactions and algorithmic operations between clinicians, patients and networked computer systems (Van Dijck and Poell 2016). In technological terms, platforms are made available through websites, smartphone applications, cloud software and the like. Yet, platforms are neither mere technological nor mere digital constructs. They become operational as part of ‘infrastructures’

consisting of technical artefacts, organisational arrangements, cultural values and social practices (Langstrup 2013). Therefore, in addition to the technological, medical and economic assessment of the platform, EmERGE conducts a ‘sociotechnical evaluation’ within an independent workpackage, led by the University of Brighton. In this workpackage, we engage with practices of design and use in order to provide insights into how people approach, imagine, anticipate and ultimately interact with new technologies. The data set underpinning the analysis in this article is drawn from the initial phase of a co-design process – before the new mHealth platform was fully developed.

### *Initiating co-design*

Social design research has recently been recognised as important means to establish the effective and responsible delivery of digital health technologies (Lupton 2017a, Lupton 2017c). Following this approach, we initiated a co-design process among patients, clinicians and technology developers to elicit current challenges of HIV care and to consider the potential uses and implications of integrating a digital platform within existing care infrastructures.

To implement co-design, we worked closely with clinicians and patient organisations – in particular, the European Aids Treatment Group (EATG) and its local partners within each study site. Together, we designed a protocol for engaging patients and clinicians alongside the iterative phases of the platform’s design and implementation. It was decided to use co-design workshops as main method to involve potential users in design activities to develop ideas and identify challenges (Lupton 2017c, Robert 2013). However, co-design workshops are also recognized as a challenging method (Robert 2013). Time-constrained clinicians as well as some of the more vulnerable and often stigmatised HIV patients can find it difficult to participate in long-lasting and collective co-design workshops. To ensure flexibility in data collection, individual interviews were considered as an alternative where participants were unwilling or unable to attend workshops.

With our clinical and patient-community partners we established a schedule for workshops and interviews. First, the idea of using a digital health platform for HIV care is presented as a narrative stimuli to identify ideas and new ways of ‘doing’ HIV care. Thereafter, co-design activities are



conducted along three phases that all draw on the ‘use situation’ as fundamental starting point for design (Halskov and Hansen 2015). First, participants are encouraged to discuss current practices of HIV care and uses of digital technologies in their everyday lives. Second, they are prompted to imagine potential functionalities and features that could be provided through digital platforms and used within HIV care. Finally, participants are encouraged to anticipate potential implications of the use of digital platforms. Together, these open areas of questioning can be seen to facilitate a range of views and experiences, including apparently contradictory ones.

Patient-community partners at each of the study sites were trained as peer-researchers to mobilise interest in the study, support the recruitment of patients and facilitate co-design workshops and interviews in the local languages in cases where participants were not fluent in English. Study approval was obtained from the Ethics Committee of the University of Brighton, the NHS Health Research Authority and from governance boards at each clinical site.

### *Recruitment and data collection*

While patients, clinicians and technology developers have been part of the co-design process, the data set for this article is focused on the patient participants. Our community partners had established contacts to patients and to the clinics and used various channels (e.g. posters, Facebook, text messages and websites) to mobilise interest among potential participants. Many patients regarded these community partners as trustworthy and knowledgeable regarding issues of confidentiality for HIV patients throughout co-design. With their support, we recruited 97 HIV patients to participate in co-design workshops and interviews. Table 1 provides demographic data on both the total patient population and the sample recruited for co-design at each clinical site. We attempted purposive sampling to recruit a diversity of patients (e.g. specifically contacting women) while accepting that fieldwork pragmatics (such as study timelines, access to potential participants, etc.) will limit its success.

Ten workshops and twenty interviews (Table 1) were conducted at the offices of community partners, at hotels, or in the clinic, depending on what was appropriate. Workshops were facilitated in

the local language by a community partner, with the academic researcher and a member of the EATG also present. An instant translator enabled the researchers to take notes and raise additional questions, as appropriate. Thirteen interviews were conducted in English by the academic researcher and seven by community partners in local languages. Throughout the data collection, the EATG member and the lead author exchanged and discussed their notes and debriefed impressions of the workshops with community partners. Workshops and interviews were audio recorded (Medium recording length: 112 and 46 minutes respectively). All recordings were transcribed verbatim and non-English transcripts were thoroughly translated. Each patient provided written informed consent prior to the interview/workshop and received €25/£20 remuneration for participation.

### *Analytic approach*

Data analysis followed coding procedures in grounded theory (Strauss and Corbin 1998). The analytic process was iterative following several steps of open, axial and selective coding. Open coding involved a sequential analysis where data was broken down by assigning first conceptual labels. In the axial coding process, preliminary concepts were partially revised and established into categories and sub-categories. Moreover, the relationships between the various categories were explored. Selective coding was performed to enhance and verify the categories. Data was primarily analysed by BM but first concepts and categories were continuously negotiated with FH and MD on a bi-monthly basis. Furthermore, preliminary findings were discussed within the whole project consortium. NVivo 11 software was used to support the management of the textual data and to organise the codes being assigned to the transcripts.

To ensure confidentiality while quoting participants, pseudonyms were assigned in the following presentation of results: indicating participant number, study site (by first two letters) and mode of data collection (WS=workshop, I=interview); e.g. P59\_An\_WS.

## **Results**

Co-design opened a reflective space where the ambivalence of digital health in the context of HIV care could be articulated. The co-design workshops constituted a ‘deliberative method’ (Abelson et al. 2003, Marent et al. 2012) through which HIV patients could articulate and share values in order to make strong evaluations of the future object. Co-design encouraged participants to reflect their initial orientations and take additional and opposite possibilities into account. We often noticed that, during the progression of workshops and interviews, participants became more ambivalent and made efforts to balance alternative and contradictory interpretations.

Most participants already had experiences with digital (health) technologies by using apps and/or engaging with digital care pathways that had already been implemented in the study sites (e.g. email in Brighton, video-clinics in Barcelona). Therefore, their understanding of the future platform was often built on established practices of handling digital technology. Participants also sometimes referred to more ‘traditional’ forms of care (e.g. the face-to-face clinical encounter) in order to evaluate how to position themselves in relation to digital health technology.

In the presentation of results, we stress ambivalence as a phenomenon that is the product of collective reflections. The notion of ambivalence allows us to elaborate conflicting demands that HIV patients discussed while anticipating potential functionalities and use-situations of the forthcoming platform. Our analysis revealed opposing orientations along three key dimensions of digitalised healthcare (Figure 1). First, *quantification* and opposing approaches to numerical representations of health; second, *connectivity* and contradictory approaches to digitised connections; third, *instantaneity* and opposing approaches to instant alerts. In the following analysis we discuss where and how ambivalence was articulated along these dimensions and provide examples of how patients navigated contradictions along *embodied* conditions and *embedded* environments.

### *Quantification: Approaches to numerical representations of health*

In the context of HIV medicine, the collection of biomarkers by means of blood tests form a key role in monitoring HIV progression (Paparini and Rhodes 2016). In the co-design process, several participants argued that a digital platform could provide patients with remote access to personal ‘blood counts’ (e.g. viral load, CD4 count, kidney and liver function) and could allow novel insights by

visualising historic trends. Participants outlined that, in the current situation, they depend on the HIV consultant as access point to their data:

‘Now I depend on the [doctor’s] screen. When I go to the doctor ... the whole computer is turned towards me and then I see colours and that it is in the red, and then that is done. Ah, well, OK. But that is very far away and ... I’m thinking, it is about my blood, it is my data ... receiving something and getting it, yes, in a modern way. I think that an app could indeed play a fantastically beautiful role’ [P57\_An\_WS, 48-years-old male]

Within patients’ reflections of whether and how remote access to personal health data could support HIV care, we identified two opposing orientations (Figure 1). On the one hand, the category ‘deliberating health knowledge’ assembles narratives that emphasise the importance of exchanging experiences within face-to-face clinical encounters and draw the distinction between ‘getting data’ and ‘being informed’ in order to make decisions about health (cf. Henwood et al. 2003, Henwood et al. 2011). On the other hand, the category ‘accessing health information’ assembles narratives that suggest regular hospital visits are a tiring routine for some HIV patients who might become adequately informed by getting data through a digital device.

In the first category, participants emphasised that the meaning of quantified data needs to be negotiated with other forms of knowledge and within the social context of HIV health. In this way, a 29-year-old man, who was, in principle, in favour of the idea of having health data available in an app, argued:

‘I go to see my HIV doctor, just because not only the HIV and the medical aspects are discussed, no application can replace that. My doctor asks: “How are you doing?” ... And that question, given that I am at the doctor’s, may just be more important to me than my numbers’ [P59\_An\_WS]

For a number of participants, the face-to-face consultation is seen as a meaningful experience where they not only get their blood counts but have the opportunity to discuss broader health issues such as engaging in intimate relationships, managing emotions, or maintaining a healthy lifestyle. Moreover, being with the HIV consultant helps some patients – particularly those who are not in employment – to overcome isolation and experience ‘warm feelings’ [P44\_An\_I] and a ‘sense of acceptance’ [P7\_Br\_WS]. The accounts in this category were critical of the potential to access blood counts and other health data through a digital platform because data are seen as a ‘reduction’ that needs careful interpretation. Therefore, some participants argued that, without the support from the doctor, patients

may lack the capacity for interpreting data and thus become (unnecessarily) scared and unsettled when retrieving results on the smartphone:

‘... anxiety about your results, because you don’t know how to interpret them, you may have a blip on your viral load and that means nothing, but if you have access you may be anxious for a couple of days before going to the doctor, and she explains to you that’s nothing’ [P23\_Li\_I; 78-years-old man]

The complexities of integrating the multiple meanings of viral load and other numerical definitions of HIV has been widely discussed in the literature (cf. Moore et al. 2001, Persson et al. 2003). In our data, particular patients with unstable HIV and comorbidities outlined that they rely on the face-to-face consultations to negotiate their complex condition and deliberate accurate measures for treatment and care. Blood counts of these patients may fluctuate and, therefore, are difficult to interpret and may unsettle the person. In this respect, data should be discussed and interpreted within the context of people’s broader health experiences in order to inform health practices. This is better achieved through a clinical encounter embedded in face-to-face interactions than by digital communication.

Conversely, ‘accessing health information’ on the smartphone was seen by some as a simple and, at times, adequate way to be informed about one’s health status. Often patients experienced regular appointments with the HIV consultant as an exertive routine (in terms of travel time and expenses to visit the clinic) required simply to ‘collect’ blood test results. Becoming informed about one’s condition was seen as a simple matter of having access to data. The patient who highlighted in the quote above the dilemma of interpreting data outside the clinical encounter, made at the beginning of the interview an opposite statement, arguing:

‘Well I will skip some consultations and will not lose so many ours waiting for the doctor if I can have this [blood test results] on an electronic way’ [P23\_Li\_I; 78-years-old man].

This statement is from the oldest study participant. It illustrates a common phenomenon in our data where age was not found to be an exclusion indicator for HIV patients’ capabilities or motivation to engage with new technology. Similarly, a 60-year-old man who is already using an HIV-related smartphone app argued:

‘I’m working ... I find it a bit difficult to say, “Oh sorry, I need to have tomorrow morning off” ... my condition is well under control ... I would like to have something sent to me and see where I am and what I’m doing’ [P14\_Br\_WS]

In such narratives, the data seem to objectify the bodily condition and, if any interpretation is needed, this could be integrated within the technology by graphs, colour coding, or borderline values that are easy to read and you ‘just glance at it and you know where you stand, basically’ [P67\_Za\_I; 40-year-old male]. It was also outlined that graphical representations of historic results could enable patients to keep track of their HIV progression: ‘to check my data all the time, to compare like what was before and now and to get some statistics about myself’ [P63\_Za\_WS; 29-year-old male]. Such engagement with quantified data, however, was mediated by patients’ HIV status. Patients proposing that access to ‘their numbers’ is an adequate measure to become informed about their health often also described their condition as well under control (suggesting that their viral load is undetectable). Therefore, they felt confident in handling medical data and sometimes argued that regular check-ups in the clinic have become a tiring routine.

### *Connectivity: Approaches to digitised connections*

During co-design, participants constituted the mHealth platform as a ‘connecting element’ [P55\_An\_WS] to share health data and facilitate communication between patients and health professionals. Reflections on the potential impact of digital connections on social relationships and privacy were characterised by ambivalence (Figure 1). The category ‘corporal presence in protected boundaries’ refers to patient accounts that suggest that increased use of digitised connections could undermine desired social relationships with professionals and, potentially, create unwanted connections that lead to the disclosure of confidential health data. In contrast, the category ‘distant presence in invisible networks’ refers to accounts that indicate the potential of digital connections to create closer relationships with professionals and to protect the privacy of HIV patients.

Narratives within the first category emphasised that it is principally the HIV consultant that tries to motivate and encourage them to keep going, particularly when personal blood results do not reflect a positive state of health. Imagining a sociotechnical assemblage where he becomes primarily connected with the clinic through a digital platform and with less support from the clinician in face-to-face interactions, a 34-year-old said:

‘I don’t know, sometimes when I feel like down, yeah, and I seeing my bloods going down and I probably be more down ... even start trying give up maybe even’ [P2\_Br\_WS]

In line with several other studies of HIV (cf. Rosengarten et al. 2004, Watkins-Hayes 2014), most of our study participants mentioned that they have built a strong relationship with their HIV consultants and were ‘loyal’ [P20\_Li\_I] to them over a long period of time. In this regard, some raised concerns that they might lose ‘that personal relationship with the consultant’ [P16\_Br\_WS] if communication moved from the physical encounter towards digital connections. Here, episodic face-to-face interactions are configured as the preferred way to maintain the relationship with clinicians. Another issue with digital connectivity related to the question of which kind of unwanted connections may be established. Privacy and security concerns are already widely reported in studies on the adoption of digital technologies in HIV care (Stablein et al. 2015, Mazanderani et al. 2013, Schnall et al. 2015) and were discussed widely by co-design participants. Some patients expressed that they do not trust the security of cloud-based systems and fear these are a threat towards their confidential data. A 33-year-old stated that while she is using social media for some purposes she would resist the use of a digital platform or app for her sensitive HIV data:

‘Even though it has codes and all kind of stuff ... this app is online ... Anybody can hack my email, anybody can hack my Facebook ... I don’t want it to maybe one day, come out ... if you say: “This app is here you can download it,” I will say: “No, thank you.” ... This [personal medical data] is something that I think is supposed to be like, on papers, and hidden somewhere deep in the basement’ [P65\_Za\_I]

Here, the networked computer systems cannot be trusted and privacy and confidentiality can best be protected by material boundaries. The potentialities of connectivity produced by digital technologies were linked closely to discussions of stigma in HIV, where concerns were raised about the potential disclosure of one’s HIV status through digital connections. As shown in the quotation above, participants who expressed distrust in the security of digital technology emphasised that they would want their health data to be stored within the boundaries of the clinic and not shared by a digital network. Moreover, the perception of stigma was also linked to the isolation and some patients described that their HIV clinician is the only person with whom they speak about their HIV. In this context, the corporal presence in episodic interactions with the clinician became an essential resource to experience warm feelings and a sense of being accepted.

In contrast, the category ‘distant presence in invisible networks’ reflects patient accounts emphasising that, by increasing the ubiquity of virtual interactions, a digital platform could create closer relationships with clinicians. In this way, a 40-year-old man argued:

‘the application could give a person a sense of being safe ... or being connected to the doctors all the time’

[P67\_Za\_I]

In this positioning, the potentiality of virtual interactions, such as messaging services and Skype functions, were significant because of their capacity to establish closer relationships with clinicians. With regard to privacy, patients also referred to digital networks as a possible way to safeguard the confidentiality of HIV patients. Several participants stated that they have trust in the security of digital technologies and emphasised that they already use these technologies for banking and other purposes. For example, a 28-year-old reported that he used an app that stored his HIV data and stated:

‘I had no qualms about having that on my ‘phone but I was terrified about being seen walking to the clinic’

[P7\_Br\_WS]

Many participants explained that they felt nervous in the clinic environment (e.g. a 41-year-old described taking a sleeping pill the night before the clinic visit [P68\_Za\_I]) because they feared encountering people they know whereby their HIV status might become disclosed. A 46-year-old man pointed out that ‘in a face-to-face environment there is little confidentiality’ [P87\_Ba\_I]. In contexts where being HIV positive is stigmatised, several participants appreciated digital connections that could reduce physical visits to the clinic (and make them ‘invisible’) and thereby protect their confidentiality.

### *Instantaneity: Approaches to instant alerts*

In current HIV medicine there is a strong focus on viral suppression as the ultimate goal of antiretroviral therapy. This has led to a close surveillance of patients’ adherence to the treatment regime (Paparini and Rhodes 2016) and, as some critics argued, to the ‘re-medicalisation’ of HIV (Nguyen et al. 2011). Adherence to the drug regime, particularly, created a considerable stress factor among many patients:

‘I know if I don’t take the pills I die, it’s as simple as that, there’s no ifs, no buts, no maybes, these things are very serious drugs that we take’ [P7\_Ba\_WS; 28-year-old male]



These concerns were reflected in how participants imagined the platform as a tool that sends instant messages and alerts to prompt medication intake or to remind for upcoming appointments. Such instantaneity forms possibilities to ‘distribute’ memory and control between patient and technology. Co-design participants highlighted the ambivalence of possible patient-technology relationships by discussing whether it brings forth an active patient that takes control over his/her health or, conversely, creates a passive patient that is being controlled by the technical device:

‘I think it’s going to be a crutch. We’re going to be active first regarding the programming of the application.

Like, I take this medication X, X, X at that time and we will wait for the mobile phone to warn us that we have to take it. I think it’s a bit of a passive role’ [P30\_Li\_WS; 28-years-old male]

Some patients outlined that their health decisions are ‘based on internal goals’, suggesting that instant alerts would be invasive to certain aspects of everyday life and that not every aspect of the everyday should become penetrated by health issues (Figure 1). On the other hand, the category ‘attentive response to technical devices’ assembles accounts that make use digital devices to take control over health practice. These patients constituted instant alerts as reassuring and were prepared to integrate health tasks next to other aspects and demands of everyday life.

Within the first category patients emphasised the importance of their own (bodily) experience, feelings and self-awareness and argued that technologies that push health data and alerts might constantly confront them with an imposed reality of their disease:

‘I know myself and I know when I don’t feel good ... Sometimes it’s better to ignore some things like that [medical data]. I mean you are living with the disease, but you don’t want to think about it every day’ [P65\_Za\_I; 33-year-old female]

Hence, these participants did not make comprehensive use of technological devices to structure and organise adherence to treatment or medication. For example, a 58-year-old patient, when asked whether he uses a reminder for his medication intake, stated:

‘No. In fact I take it when I get up from bed, eat something and take the medicines in the morning and after dinner ... according to my natural schedule’ [P22\_Li\_I].

By following personal schedules and plans, these participants constituted technology that pushes data and reminders as invasive, disrupting practices of everyday life and exposing patients to the ‘risk of getting obsessed’ with their condition and ‘being permanently in alarm mode’ [P88\_Ba\_I]. Patient

accounts within this category refer to practices as temporally structured in a way that leads them to follow certain tasks, plans or goals as part of discrete social situations. In this context, instant prompts from a digital health device are understood as disruptive to the meaning and purpose of the given situation.

Other patients stated that they appreciated digital tools that give instant advice on their health status, prescribed medicines, medical appointments, and send alerts for taking medication. They also elaborated how they already use technologies to manage their health. A 49-year-old man, who introduced himself as an advanced smartphone user, explained:

‘[I] set my ‘phone up so it’s dead on six o’clock it goes off and I know that, okay, I’ve got to take meds now, because I could be doing work and I could be in the middle of something’ [P9\_Br\_WS]

The quotation refers to a form of sociotechnical practice that delegates control over when to take medication to the mobile ‘phone. The intrusion and overlaying of work practice by alerts is part of this patient-smartphone interaction. Although medication reminders are already largely used, several patients argued that, through an app, a more comprehensive and effective/intrusive sociotechnical system could be provided – one ‘that just keeps reminding you until you do it [taking the medication]’ [P64\_Za\_I; 35-years-old male]. Participants who positioned themselves as advanced users of digital technologies – by showing us their up-to-date smartphones and emphasising the apps they were using for all aspects of social life – experienced and responded to instant alerts quite differently to those participants who stated that they hardly engaged with digital technology. In sociotechnical relations of advanced users and their smartphones, (health) practices were (already) constituted as an attentive response to prompts from digital devices. These sociotechnical practices are layered through the simultaneity of pursuing different tasks next to each other – in some way this form of practice is also reflected by the smartphone screen in which apps for different purposes are situated side-by-side. Rather than dealing with health at specific and allocated times, these practices were attempting to solve health issues immediately. The alerts from the digital device were not seen as disruptive but as requiring a short attention towards medical issues that allows patients to indulge in everyday practices without constantly worrying about their health.

### Discussion

In this article we have conceptualised ambivalence as a reflexive approach to evaluate the potential implications of digital health. On a practical level, this approach advocates participatory design initiatives (Lupton 2017c, Benjamin 2011) that recognise the need to engage with a broad range of potential users and non-users (Hyysalo et al. 2016) to continually review prospective aims and consequences of utilising digital health. Responsible research and innovation in the field of digital health requires us to embrace ambivalence rather than seek to resolve contradictions and avoid conflicts. We have shown how, together with our partners in the HIV community, we set up a co-design space where patients were encouraged to articulate their various approaches, imaginations and anticipations towards a forthcoming mHealth platform. This space generated new possibilities for understanding and action which are continuously translated into the development and implementation of a prototype platform across our five study sites (Marent et al. forthcoming).

We have also mobilised the concept of ambivalence in the analysis of data collected in these co-design spaces. On an analytical level, we approached the ambivalence of the digital health platform by delineating how patients navigated tensions arising from the potential of remote access points to quantified data (Ruckenstein and Schüll 2017), the possibilities of digitised connections to healthcare providers (Van Dijck and Poell 2016), and the unprecedented forms of instantaneity that enable or take control over health practices. The notion of ambivalence accepts the simultaneous existence of two opposing orientations, perspectives or positionings and ‘facilitates both/and thinking’ (Ashforth et al. 2014, p. 1465). In the dimension ‘quantification’, we outlined how increased access and use of numerical representations of health can facilitate both knowledge and nonknowledge or, respectively, certainty and uncertainty. The spatiotemporal disembedding of medical data (Nettleton 2004, Henwood et al. 2011) formed contradictions as to whether this data can be accepted as a simple ‘objective’ information about one’s complex health status or whether it requires further negotiations with other forms of knowledge. The dimension ‘connectivity’ demonstrated how digitised connections have the potential to produce closeness and distance and privacy and exposure. In line with other studies of digitally-mediated care (Pols 2012), our co-design participants outlined how digital connections can

both facilitate and impede long-established relationships with health professionals. In this regard, researchers have recently begun to investigate how closeness and distance materialise in ‘digital atmospheres’ (Tucker and Goodings 2017, Lupton 2017b). In relation to privacy, co-design participants stressed that digital forms of connectivity will increasingly render the patient ‘invisible’ in the material space but, potentially, increase his or her visibility through the data traces left while navigating the virtual space. In the dimension ‘instantaneity’, we outlined the contradictory forms of control within patient-technology relationships, showing that the adoption of digital memory and instant alerts within practices of care is simultaneously rendering the patient as active and passive participant.

Having these multiple dimensions of ambivalence available may offer a more nuanced framework to the widely studied phenomena of ‘resistance to’ or ‘acceptance of’ digital health technologies (cf. Fox and Connolly 2018) as well as facilitating a wider range of views and experiences when engaging stakeholders in co-design for digital health. Conceptualising multiple dimensions of ambivalence in separate continuums offers the possibility to observe different positionings along different dimensions (Piderit 2000). In our analysis, we found that most patient accounts towards the digital platform were neither consistently negative (implied by the notion of ‘rejection’) nor consistently positive (implied by the notion of ‘acceptance’). While individual patients sometimes unequivocally accepted the concept of the digital platform in one dimension (e.g. quantification: ‘I want to access to my patient history and see where I am on a scale’) they might have rejected it in another dimension (e.g. instantaneity: ‘I would not use reminders, these are invasive’). Therefore, ‘cross-dimension ambivalence’ (see particularly: Piderit 2000), understood as the acceptance of some technological affordances while rejecting others, was the most prevalent type of ambivalence found within accounts of individual patients. We thus argue that a multidimensional framework of ambivalence permits a more integrative view of the ways in which patients may dis/engage with digital health technologies.

A further contribution of this article is that it offers empirical evidence to support the notion that ambivalence cannot be reduced to an individual experience but is configured through a web of relationships that are embedded within situated practices (Hillcoat-Nallétamby and Phillips 2011, Arribas-Ayllon and Bartlett 2014). Having facilitated ambivalence through a collective co-design process, we generated an understanding of its relational properties. Imagining potential scenarios of

digitised HIV care from the accounts of a diverse set of patients across different countries revealed how meanings and tensions shift along socio-material conditions and environments. Without the space for a detailed comparative analysis, the data presented in this article offers concrete examples of how tensions conceptualised and anticipated with the digital platform were *embodied* by bodily conditions (e.g. stable HIV) or patient histories (e.g. experience with technologies) and *embedded* in social situations (e.g. unemployment), human relationships (e.g. with consultant) or organisational and cultural environments (e.g. distance to clinic, stigma). We have therefore demonstrated, empirically, how a relational approach to ambivalence can counterbalance fatalistic and optimistic accounts of technology and open the way for critical studies that explore how tensions of technologies are constituted and managed within situated practices (Sharon 2017).

In current societies, the digital has been portrayed as a ‘total social fact’, touching on most aspects of social life (Marres 2017). This makes it challenging for social scientists to act as distant critics *of* the digital (Ruckenstein and Schüll 2017, Lupton 2018, Hine 2015) and has led to calls for social scientists to take up their critical role *within* the configuration of digital interventions. In this article, we have discussed how we have done this through our co-design work in a large-scale EU mHealth project in the field of HIV care. We have proposed, and demonstrated empirically, the value of ambivalence as a reflexive concept that can support such critical and engaged approaches to digital health. We also aim to have made clear how critical and engaged approaches to digital health must take issue with the notion that co-design should be limited to the initial design phase and that tensions and contradictions about digital health can be resolved through early design choices. Instead, co-design continues in use and, whilst modifications to technical aspects of the new platforms and apps may still be made, ambivalence will continue to be present as users navigate new care pathways alongside embodied conditions and embedded practices.

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## AMBIVALENCE IN DIGITAL HEALTH

Table 1 Participants sample and distribution of data collection across clinical sites

	ANTWERP (An)		BARCELONA (Ba)		BRIGHTON (Br)		LISBON (Li)		ZAGREB (Za)		Total sample
	Patients in clinic follow- up (2014)	Patients in co-design (2016)	Patients in clinic follow- up (2014)	Patients in co-design (2016)	Patients in clinic follow- up (2014)	Patients in co-design (2016)	Patients in clinic follow- up (2014)	Patients in co-design (2016)	Patients in clinic follow- up (2014)	Patients in co-design (2016)	
<b>Number</b>	2570	19	4757	22	2241	19	4846	22	862	15	<b>97</b>
<b>Male/female Ratio</b>	2.8	17/2 8.5	4.1	20/2 10	7.3	14/5 2.8	2.5	15/7 2.1	6.8	12/3 4	<b>78/19 4.1</b>
<b>Mean age STD/min/max</b>	45.1	44.1 12.1/27/65	44.9	45.1 10.3/23/61	46	44.6 10.8/28/68	48.5	45.1 12.1/28/78	43.8	38.1 8.1/24/50	<b>43.7 10.9/23/78</b>
<b>Age&gt;50</b>	848 (33%)	5 (26.3%)	1454 (30%)	6 (27.3%)	848 (37.8%)	6 (31.6%)	2043 (42.1%)	6 (27.3%)	234 (27.4%)	0	<b>28 (28.9%)</b>
<b>MSM*</b>	1064 (41.4%)	15 (78.9%)	2648 (55.7%)	18 (81.8%)	1761 (78.5%)	12 (63.2%)	-	9 (40.9%)	561 (66%)	9 (60%)	<b>63 (64.9%)</b>
<b>Non-nationals</b>	907 (35.3%)	5 (26.3%)	2213 (46.5%)	1 (4.5%)	665 (29.7%)	8 (42.1%)	-	4 (18.2%)	7 (0.9%)	0	<b>18 (18.6%)</b>
<b>Workshops Patients per WS</b>		2 10/6		2 10/6		2 8/9		2 8/10		2 7/3	<b>10</b>
<b>Interviews</b>		3		6		2		4		5	<b>20</b>

\*MSM: men who have sex with men

## AMBIVALENCE IN DIGITAL HEALTH

Figure 1 Multidimensional reflections of ambivalence towards using digital health in HIV care

